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Home care management among mothers having children with cerebral palsy in Erbil city

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Abstract

Background and objective: Care for children with disabilities is often neglected and ignored. It tend not to be taken outside the home because of embarrassment and potential teasing and ridicule from others. Home care is the best way to provide daily care and management for children with chronic disabilities. This study was designed to assess the practices of mothers of children affected by cerebral palsy regarding home care management in Erbil city/Iraqi Kurdistan region.

Methods: A cross-sectional study was carried out during the period from July 1, to September 1, 2012. A convenience sample was taken, involving 100 mothers whom weekly or monthly attended Helena Center for Handicapped Children for physiotherapy and medical managements.

Results: The results revealed that less than half of the mothers were between 24-30 years old, half of them were illiterate, most of them were living with low socioeconomic status, and more than half were living in urban areas. The highest percentage of cerebral palsy children were in toddler developmental stage, the majority complained of spastic type. The present study found that there was significant association between mothers' age and dental/oral care. There was also significant association between socio-economic status with both of dental/oral care and child safety. There were highly significant association between ages of cerebral palsy children with maintained oral care and hygiene, nutrition, hydration care and constipation. There was significant association between types of cerebral palsy and communication.

Conclusion: The finding of the study refers that the mothers having cerebral palsy child, complained of inadequate skills concerning home care management, and the study recommends a comprehensive health education program for mothers having cerebral palsy child.

Keywords: Home care. Management. Mother. Children. Cerebral palsy.

Introduction

Cerebral palsy (CP) is one of the chronic conditions which have become a serious health burden worldwide. Culture plays an important role of caring over a long time in childhood.[1] CP is the most common cause of significant motor impairment in childhood, occurring in 2.5 children per 1000 live births.[2] Now, there are around 1700 children registered in Helena Center for Handicapped Children with CP in Erbil city. Their ages are between one to seventeen years old.[3] Children with CP or other neuro-developmental disability need various professionals health care, such as pediatric nurse and neurologists. They often have complex long-term by a family-centered service delivery model.[4] Usually those children have difficulty with speech or no speech, intellectual and communication impairment are of similar magnitude to the combined effect of social factors such as parental education, parental employment, and family structure.[5] This group of pediatric patients needs continuous care and supervision. The primary care management of cerebral palsy provides an opportunity to implement the medical home care, and improve the overall quality of care of affected

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individuals and their families.[6] Home-based programs are necessary because almost none of parents have received appropriate training for working with children with neurological disorders.[7] Likewise, despite efforts to enhance home care, the National Health System in Spain depends heavily on outpatient clinic-based care and there are few opportunities for home care. Thus, the responsibility and pressure on the caregiver is high.[8] Understanding the priorities, necessity of children and youth with CP and their families are essential for family centered service.[9] A study done on families having CP child emphasized that most of the families had showed great openness toward acquiring new skills and knowledge for handling their children with chronic disability. Lack of home care management towards disabled children is the result of poor awareness and knowledge about the disability.[10] More recently, social policy has promoted community-based programs that provide care for children with disabilities in their homes and community.[11] Nurses can support and provide health education to the mothers and family members about meeting the needs of those children. Nurses should also encourage the rehabilitation of the children to improve their function.[12] Home care is a good choice for many children who have chronic condition; a mother is the main provider of physical and emotional support for the patient at home.

Methods

A cross-sectional study (survey) was carried out to assess the practices of the mothers regarding home care management. Helena Center for Handicapped Children was selected for data collection. This center was established in 1993 by a Swedish 'volunteer' woman named Helena. It is located in Shorsh Street; Erbil city. It is the first center providing medical care and physiotherapy to children who have one type of handicap or more. Data was collected during the period extended from 1st July to 1st September 2012. A sample of 100 mothers having children with CP were recruited for the study. Official permission was obtained from Erbil General Directorate of Health and Helena Center for Handicapped Children. Data collection was done by the researcher, who kept the confidentiality and anonymity of the data. The purpose of the study was explained; and a verbal agreement was obtained from the participants. A questionnaire was used concerning home care management of mothers having CP children. It consisted of two parts. The first part was divided into two sections, section one was concerning demographic characteristics of mother such as age, formal years of education, and socio-economic status (SES), and section two was focusing on CP child's demographic information such as developmental stage, gender, and types of CP. The second part was to assess mother's home care management skills, and it consisted of skin care (4 items), dental/ oral care (5 items), maintain oral hygiene (4 items), nutrition and hydration (8 items), bowel and bladder functioning (6 items), constipation care (4 items), child safety (7 items), communication (8 items), behavioral and emotional care (11 items). The items were rated between (1) for yes, and (2) for no. Direct interview technique was used with whom kindly accepted to participate in the study. Data was analyzed by using the statistical package for social science (SPSS, version 18). Basic descriptive frequency and Chi square test were used to test association between variables. A 'P' value of ≤ 0.05 was considered as statistically significant.

Results

The results revealed that mean age (±SD) of mothers was 32.53 (±8.37) years old, 43% were illiterate, 65% were of low SES and 56% were living in urban areas (Table 1). The mean age (±SD) of children with CP was 4.376 (±3.35). More than half (53%) of CP children were toddler developmental stage. The highest percentages (78%) were having spastic type (Table 2).

The study found that there was significant association between age of mother and dental/oral care (P = 0.024), and revealed that the age between 24-30 neglected the home care rather than the others (Table 3). There was significant association between SES and dental/oral care (P = 0.039), as shown in Table 4. There was highly significant association between SES and child safety measurement (P = 0.001), as shown in Table 5. There was highly significant association between age of CP children versus maintained oral hygiene (P < 0.001) as shown in Table 6. There was significant association between age of CP children with nutrition and hydration care (P < 0.001) (Table 7). There was significant association between age of CP children and constipation (P < 0.001) (Table 8). There was significant association between types of CP and communication (P = 0.042) (Table 9). There was significant association between gender of CP and communication (P = 0.024) as shown in Table 10.

Table 1: Demographic information of mothers' CP child

Variables	F.	%
Age of mothers / years		
17-23	**16**	**16**
24-30	**35**	**35**
31-37	**30**	**30**
38-44	**10**	**10**
Above 44	**9**	**9**
Mean and SD	**32.53 ± 8.37**	
Level of mothers education		
Illiterate	**43**	**43**
Can read and write	**6**	**6**
Primary graduate	**30**	**30**
Secondary graduate	**14**	**14**
High college graduate	**7**	**7**
Socio-economic status (SES)		
Low	**65**	**65**
Middle	**31**	**31**
High	**4**	**4**
Residency areas		
Urban	**56**	**56**
Rural	**44**	**44**
Total	**100**	**100**

Table 2: Demographic information of CP child.

Variables	F.	%
Developmental stage		
Toddler	**53**	**53**
Preschool age	**25**	**25**
School age	**22**	**22**
Mean and SD	**4.376 ± 3.35**	
Sex		
Male	**59**	**59**
Female	**41**	**41**
Cerebral Palsy types		
Spastic	**78**	**78**
Athetoid	**11**	**11**
Ataxia	**8**	**8**
Mixed	**3**	**3**
Total	**100**	**100**

Table 3: Association between age of mother and Dental/ oral care.

Dental/ oral care **Age of mother years**	Yes F. (%)	No F. (%)	Total	
17-23	1 (6.3)	15 (93.8)	16	
24-30	2 (5.7)	33 (94.3)	35	x^2 = 11.24
31-37	4 (13.3)	26 (86.7)	30	df=4
38-44	4 (40)	6 (60)	10	p value =.024
Above 44	0 (0)	9 (100)	9	
Total	11 (11)	89 (89)	100	

Table 4 : Association between socioeconomic status and Dental/ oral care.

Dental/ oral care **Socioeconomic status (SES)**	Yes F. (%)	No F. (%)	Total	
Low	6 (9.2)	59 (90.8)	65	x^2 = 6.478
Middle	3 (9.7)	28 (90.3)	31	df=2
High	2 (50)	2 (50)	4	
Total	11 (11)	89 (89)	100	p value=.039

Table 5 : Association between socioeconomic status and child safety.

Child safety **Socioeconomic status (SES)**	Yes F. (%)	No F.(%)	Total	
Low	7 (10.8)	58 (89.2)	65	
Middle	4 (12.9)	27 (87.1)	31	x^2 =12.957
High	3 (75)	1 (25)	4	df=2
Total	14 (14)	86 (86)	100	p value =.001

Table 6: Association between age of CP child and maintain oral hygiene**.**

Maintain oral hygiene **Developmental stage of CP child**	Yes F. (%)	No F.(%)	Total	
Toddler	0 (0)	53 (100)	53	x^2 = 14.475
Preschool age	1 (4)	24 (96)	25	df=2
School age	5 (22.7)	17 (77.3)	22	p value= <.0001
Total	6 (6)	94 (94)	100	

Table 7: Association between age of CP child and Nutrition and hydration care.

Nutrition and hydration care **Developmental stage of CP child**	Yes F. (%)	No F.(%)	Total	
Toddler	1 (1.9)	52 (98.1)	53	x^2 =14.337
Preschool age	1 (4)	24 (96)	25	df=2
School age	6 (27.3)	16 (72.7)	22	p value= <.0001
Total	8 (8)	92 (92)	100	

Table 8: Association between age of CP child and Constipation care.

Constipation care **Developmental stage of CP child**	Yes F. (%)	No F. (%)	Total	
Toddler	0 (0)	53 (100)	53	x^2 =18.660
Preschool age	0 (0)	25 (100)	25	df =2
School age	5 (22.7)	17 (77.3)	22	p value= <.0001
Total	5 (5)	95 (95)	100	

Table 9: Association between type of cp and Communication.

Communication **Types of cp child**	Yes F. (%)	No F. (%)	Total	
Spastic	14 (24.6)	43 (75.4)	57	x^2 =8.191
Athetoid	0 (0)	8 (100)	8	
Ataxia	1 (3.6)	27 (96.4)	28	df=3
Mixed	2 (28.6)	5 (71.4)	7	p value=.042
Total	17 (17)	83 (83)	100	

Table 10: Association between sex of CP children and communication.

Communication **Sex of CP child**	Yes F. (%)	No F. (%)	Total	
Male	6 (10.2)	53 (89.8)	59	x^2 =4.758
Female	11 (26.8)	30 (73.2)	41	df = 1
Total	17 (17)	83 (83)	100	p value= .029

Discussion

The findings of the present study show that the mean age of mothers was 32.53 years old. Less than half of them were illiterate, living with low SES, and more than half of them were living in urban areas. This result is in agreement with a study done by Mualla *et al* in Erbil city in 2008 who found that the majority of CP caregivers' ages were between 25-38 years old, most of them illiterate (60%), 79% were living in low SES, and 65% living in urban areas.[12] Others found that the mothers had a mean age of 40.3.[7] The family demands related to care could preclude a family member from receiving a promotion or results in the loss of a job. Medical visits, therapy, special equipment, medicines, and other specialized services were part of the financial demands associated with chronic illness for those families who were already financially stressed. Chronic illness could place them at additional risk of draining their resources.[13] The present study shows that the mean age of CP children was 4.376 years old, more than half were males, and the majority of them complained of spastic type. A similar study that was also conducted in Erbil city found that half of CP children were in preschool age, more than half were males, and the highest percentages (80%) of them complained of spastic type.[12] Another study found that the rate between males and females ratio were 1.3:1 (56% male and 44% female).[13] In a phenomenological study that was conducted in the United State of America (USA) found that the spastic CP type recorded high percentages, and added that the victim males were more than females.[14] A similar study has found that the spastic type represent 70-80%, athetoid or dyskinitic type was 4-8%, ataxic type was 5 -10% and mixed type was 1-2%.[15] Another study from Nigeria found that half of CP children were in toddler developmental stages.[2] The present study shows a significant association between mothers' ability towards oral/dental care and mothers' level of educational and SES. This result is supported by a study done by Canadian Pediatric Society (CPS) where the caregivers with low SES reported more problems concerning their patients because of the limited resources and reduced capacity to provide adequate care.[16] Others stated that dental care could require special attention to the consequences of altered oral motor tone, dysplasia, bruxism, tongue movements, mouth breathing, and challenges to dental hygiene maintenance.[17] Similar studies stated that the caring for a child with CP was affected by SES.[18] Another similar study emphasized that low SES considered one factor which affected mothers' nurtures of the child. This could occur because several studies have shown associations between low income and poor oral health. Families from low SES group lack of knowledge which led to poor home care management skills[6]. The SES is considered one factor which affects mothers' nurtures of the children care. Families from low SES group had lack of knowledge which led to poor skills.[12,15] The present study found that there are significant association between SES, and child's safety. This result was supported by London *et al* who emphasized that the mothers were affected by poverty, low education levels, and lacks of family and community support.[15] Others stated that safety belts should be used for children in strollers and wheelchairs; especially with a child with chronic seizure wearing a helmet to protect against further injury[19] The situation refers how the SES of the family has significant impact on the way of raising a child with CP.[1] The finding of the present study shows a significant association between CP developmental stage and oral hygiene, nutrition, and constipation. This result was in agreement with a study stated that the evaluation could require a thoughtful but systematic review of potential causes including dental pain, gastroesophageal reflux, constipation, orthopedic pain, and urinary tract problems, including kidney stones, and needs special nutritional care[13]. Others emphasized that the children with CP required high-calorie diets or supplements to the diet because of feeding difficulty associated with spasticity. Many children had difficulty with chewing and swallowing. Giving the child small amount of soft food at time was the best way to provide hydration. Children with physical disabilities showed that parents were concerned about nutrition and physical activity, social life, future productivity, daily routines, and balancing their adolescents' need for independence with safety and energy conservation.[20] Others stated a self-feeding and nutrition was concerns of families of young children and children with severe motor limitations and could reflect parents' concern for their children's growth, dental care, skin care and general health status.[9] Altered smooth muscle and sphincter tone together with the effects of medications, diminished activity, and variable hydration contribute to the high incidence of constipation in children with CP.[14] The study found that there was significant association between types of CP, sex, with communication. Also the present study revels that there was significant association between parent's communications with CP children. Others stated that the CP described a group of disorders of posture and movement accompanied by impairments in sensation, perception, cognition, and communication, because CP children have difficulty with speech or can not speak.[5,10] Others stated that the majority of research assistants were health care professionals experienced in complication during collection of data because of child's communication.[9] Other studies described that poor parent–child communication increased the risk of psychosocial problems in school-aged children.[21] Others recommended that the speech therapy aims at improving communication. A child need help to overcome a slight articulation problem, or she may not be able to communicate verbally and may require a non-verbal communication system. They added that 80.6% mothers also isolate themselves and even reduce their social communications to as few people as possible.[22] Other stated that the brain injury resulting in cerebral palsy may also affect higher cognitive functioning, resulting in evidence of learning disability, language and communication impairment.[6]

Conclusion

Most mothers were in child bearing age. The disabilities were mainly due to financial problems rather than inadequate preparation to care for the child or lack of information regarding the condition. The study recommended that the health education program should be provided by nurses to mothers having CP child in order to have good home care management.

Conflicts of interest

The author reports no conflicts of interest

References

1. Klankaradi K. Never-ending caring: the experiences of caring for a child with cerebral palsy. A thesis presented in fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing at Massey University, Palmerstone North, New Zeland; 2008.
2. Tella BA, Gbiri CA, Osho OA, Ohunrinu AE. Health-related Quality of Life of Nigerian Children with Cerebral Palsy. DCID: 2011;22 (1): 95-105. Available form: www.dcidj.org.
3. Helena Center for handicapped children. Annual Census Document; 2012.
4. King S, Teplicky R, King G, Rosenbaum P. Family -Centered Service for Children with Cerebral Palsy and Their Families: A Review of the Literature. Semin Pediatr Neurol 2004;11(1): 78-86.
5. Dickinson HO, Parkinson KN, Ravens-Sieberer U, Schirripa G, Thyen U, Arnaud C, et al. Self-reported quality of life of 8–12-year-old children with cerebral palsy: a cross-sectional European study. Lancet 2007; 369 (30): 2171–8. Available from: www.thelancet.com.
6. Cooley WC. Providing a Primary Care Medical Home for Children and Youth with Cerebral palsy. Pediatrics 2004;114:1106-13. Available from www.pediatrics.org.
7. Paula JS, Leite I CG, Almeida AB, Ambrosano GMB, Pereira AC, Mialhe F L. The influence of oral health conditions, socioeconomic status and home environment factors on school children's self perception of quality of life. Health Qual Life Outcomes 2012;10(6): 1-20. Available from: http://www.hqlo.com/content/10/1/6.
8. Caldero C, Gomez-Lo´ pez L, Martı´nez-Costa C, Borraz S, Moreno-Villares JM, Martinez-Giner CP. Feeling of Burden, Psychological Distress,

and Anxiety among Primary Caregivers of Children with Home Enteral Nutrition. J Pediatr Psychol 2011; 36(2):188–195. Available from http://jpepsy.oxfordjournals.org.

9. Chiarello LA, Palisano R J, Maggs JM, Orlin MN, Almasri N, Kang LU, et al. Family Priorities for Activity and Participation of Children and Youth with Cerebral Palsy. Phys Ther 2010; 90: 1254-64.
10. Murphy NA. Parent-Provider-Community Partnerships: Optimizing Outcomes for Children with Disabilities. Pediatrics 2011; 128 (4): 795-803.
11. Hanprasitkum Ch, Wichiencharoen K, Seeda R, Priyatruk P. Caregivers’ Needs for Caring Cerebral Palsy Children at Home. Thai J Pediatric Nurs 2001; 1(1): 89-99.
12. Mu'ala E, Rabati A, Shwani S. Psychological Burden of a Child with Cerebral Palsy upon Caregiver in Erbil Governorate. The Iraqi postgraduate medical journal 2008; 7 (2): 129-34.
13. Flanagan AY. Families of chronically ill patients, American Nurses Crediting Center's (ANCC), CME Resource 2010; 30:1-38.
14. Glasscock R. A phenomenological study of the experience of being a mother of a child with cerebral palsy. Pediatr Nurs J 2000;26 (4): 407-10. Available from: http://www.ncbi.nlm.nih.gov.
15. London ML, Ladewig PW, Ball JW, Bindler RC. Maternal and child nursing care, 2nd edition. New Jersey: Person education; 2007. P.1702-7.
16. Canadian Pediatric Society (CPS). The child with multiple Impairments. Pediatr Child Health 2000; 5(7): 397-402.
17. Schwartz MW, Bell LM, Bingham PJ, Chung EK, Cohen MI, Friedman D, et al . The 5 – minute pediatric consult. 3rd edition. London, UK: Lippincott Williams & Wilking; 2003. P. 230-1.
18. National Center on Birth Defects and Developmental Disability (NCBDDD): Economic costs Associated with Mental Retardation, Cerebral Palsy, Hearing Loss, and vision impairment . United States. MMWR 2004;53 (3): 57-9. Available from: http://www.cdc.gov/
19. Arksey H, Beresford B, Glendinning C, Greco V, Sloper T. Outcomes for parents with disabled children and careers of disabled or older adults: Similarities, differences and the implications for assessment practice. Social Policy Research Unit, University of York; 2007. P. 1-22. Available form www.york.ac.uk/spru.
20. Datta P. Pediatric Nursing. New Delhi, India: Jaypee brothers medical publisher; 2008. P. 397.
21. Antle BJ, Mills W, Steele C. An exploratory study of parents’ approaches to health promote in families of adolescents with physical disabilities. Child Care Health Dev 2008; 34:185–93.
22. Jinming Z, Jianjun L. Survey of mothers of children with cerebral palsy. Intern NGO J 2010; 5(5): 129-2. Available from http:// www.academicjournals.Org / INGOJ.